Complete Summary

GUIDELINE TITLE

Recommendations for preparing children and adolescents for invasive cardiac procedures: a statement from the American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in collaboration with the Council on Cardiovascular Diseases of the Young.

BIBLIOGRAPHIC SOURCE(S)

LeRoy S, Elixson EM, O'Brien P, Tong E, Turpin S, Uzark K. Recommendations for preparing children and adolescents for invasive cardiac procedures: a statement from the American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in collaboration with the Council [trunc]. Circulation 2003 Nov 18;108(20):2550-64. [100 references] PubMed

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Congenital heart disease requiring invasive cardiac procedures

Note: The term "invasive procedure" pertains primarily to diagnostic or interventional cardiac catheterization and cardiovascular surgery.

GUIDELINE CATEGORY

Counseling
Management

CLINICAL SPECIALTY

Cardiology
Family Practice

Nursing
Pediatrics
Psychiatry
Thoracic Surgery

INTENDED USERS

Advanced Practice Nurses
Health Care Providers
Nurses
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

GUIDELINE OBJECTIVE(S)

- To facilitate systematic implementation of preprocedure preparation for pediatric patients undergoing invasive cardiac procedures
- To describe evidence-based interventions that may be beneficial for children undergoing invasive cardiac procedures and their parents
- To delineate subgroups of children to target effective preprocedure preparation
- To identify resources needed to implement these interventions programmatically

TARGET POPULATION

Children undergoing invasive cardiac procedures between the developmental ages of 3 and 18 years and their families or caregivers

INTERVENTIONS AND PRACTICES CONSIDERED

Evaluation

1. Assessment of the children´s and parents´ current level of understanding and emotional response to the planned procedure in terms of:
    - The child´s developmental level and coping style
    - The patient´s and caregivers´ understanding of the medical condition and planned procedure
    - Previous hospital experiences, particularly adverse ones
    - Current emotional, cognitive, and physical symptoms and perceived health of the patient
    - General and procedure-specific fears
    - Family composition, including language, cultural, and religious factors
    - The method in which information is best processed by the patient and the caregivers (i.e., verbal, visual, written, sensory)
    - Other family stressors (i.e., financial, transportation, social, and other health issues affecting family members)
    - Family/caretaker coping styles and modes of decision-making

Counseling/Management

1. Provision of information including:
    - Verbal
    - Written
    - Audiovisual/video/compact disc
    - Preoperative classes
    - Hospital tours
    - Medical play
    - Internet resources
2. Coping skills training including:
    - Guided imagery
    - Positive self-talk
    - Muscle relaxation
    - Conscious breathing
    - Refocusing
    - Biofeedback
3. Play therapy
4. Peer modeling/counseling

MAJOR OUTCOMES CONSIDERED

- Anxiety levels in patients and family members/caretakers
- Patient cooperation and adjustments during and between medical procedures
- Postprocedure recovery
- Sense of mastery and self-control for patients and family members/caretakers
- Trust between patients, family members/caretakers, and health care providers
- Long-term emotional and behavioral adjustments in patients and family members/caretakers

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Key words used in the data search were adolescents, children, cardiac catheterization, cardiac surgery, preparatory intervention, congenital heart disease, and coping. Reference lists and bibliographies from review articles were the source for additional references.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus
Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence for Efficacy of Interventional Methods

A. Data derived from multiple randomized controlled trials
B. Data derived from single randomized trial or nonrandomized studies
C. Consensus opinion of experts

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

These guidelines and recommendations are based on comprehensive review of research literature by a panel of experts, with additional review of the proposed guidelines by expert consultants representing child psychiatry, child life, and parents.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

A team of expert consultants representing child psychiatry, child life, and parents reviewed the guideline recommendations and are acknowledged in the original guideline document.

This statement was approved by the American Heart Association Science Advisory and Coordinating Committee on September 19, 2003. It was published in Circulation 2003;108:2550-2564.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

The type of supporting evidence is identified for some of the interventions recommended (e.g., A, B, C). See Definitions of the evidence levels at the end of the "Major Recommendations" field.

Methods for Procedure Preparation

Research regarding the efficacy of procedure preparation generally indicates that outcomes are enhanced by (1) active participation by children and family member/caregivers; (2).personal interaction with health professionals (compared with only watching a videotape or reading a pamphlet); (3) developmentally appropriate timing and content; and (4) comprehensive stress management programs that provide information, supportive counseling, and coping-skills training. Issues about intensity, rehearsal, reinforcement, and timing require further investigation. Because of the prolonged time periods and intensity of the procedures involved, many of the interventions must integrate cognitive-behavioral methods with pharmacological therapies for pain and/or anxiety.

Tables 1 and 2 below provide a summary of possible interventions and age-appropriateness.

Table 1: Interventions for Preparing Children Before Cardiac Catheterization or Cardiac Surgery*

Intervention	Description	Benefits	Limitations
Information giving: verbal	Verbal description of the rationale for procedure and what to expect. Enhanced by descriptions of anticipated sensory experiences.	Consistent with information seeking as a dominant coping method. Permits individualization of information given. Promotes trust between child/family member and caregiver. Enhances efficacy of self-directed teaching materials	Processing of information affected by emotional responses to stress. Difficult to achieve consistency in information given. Relies on family´s memory/perception of information given. If sole intervention

Intervention	Description	Benefits	Limitations
		(e.g. written, audiovisual)	used, may increase anxiety in children with previous experience
Information giving: written	Written materials about the procedure/what to expect/anticipatory guidance regarding child/family responses/ways to promote positive coping/available resources	Efficient way to ensure consistent and complete transmission of important information. Available to family for later reference	Availability of appropriate materials. Relies on reading abilities/ habits of child/family. Difficult/ expensive to individualize information given.
Information giving: hospital tours and preoperative classes	Preoperative classes: scheduled group classes aimed at providing basic information about what to expect. Tours: may be group or family-based tour of hospital unit(s)	Effective means to present sensory information: sights/sounds/tactile experiences. Permits play experiences with medical "props."	Requires travel to referral center before procedure. Scheduling issues. Difficult to individualize information given.
Coping skills training: progressive muscle relaxation, guided imagery, conscious breathing, positive self-talk	Cognitive-behavioral skills aimed at promoting relaxation, self-mastery. Progressive muscle relaxation: focused attention on relaxation of all major muscle groups. Guided imagery: replaces fearful thoughts with visualization of peaceful, nurturing scenes. Conscious breathing: focused attention of breathing to enhance relaxation Positive self-talk: learned consciousness of replacing negative, fearful thoughts with reassuring, positive messages to self	Effective method for anxious patients who have had previous negative medical experiences, those who require repeated medical procedures, high anxiety levels.	Generally requires professional "coaching" and 4 to 6 weeks of practice before medical encounter. Efficacy often enhanced by presence of "coach" during procedure. Less effective for children undergoing prolonged procedures Requires child´s ability to engage in self-regulating behavior

Intervention	Description	Benefits	Limitations
Biofeedback	Promotes conscious relaxation via feedback provided by physiological monitoring equipment	High acceptance by children	Minimal data supporting efficacy. Requires skilled professional and sophisticated monitoring equipment. Training period: approximately 6 wk.
Play therapy	Use of directed play activities to provide information and process stressful experiences	Highly effective method that incorporates child´s usual means of processing information/life experiences	Requires age-appropriate toys, medical "props," activity area
Attention diversion techniques/distraction	Incorporates various methods of redirecting child´s focus away from stressful stimuli	Powerful intervention for young children, sensitized children, and when preprocedure preparation in advance is not possible	Requires focused attention of health care provider to engage child´s attention, although this may be a role that parents can assume. Requires availability of books, games, video, music
Peer modeling	Uses a variety of methods (videotape/written/audio-visual) to demonstrate positive coping during similar circumstances	Effective method for adolescents and naive children	May increase anxiety in children with previous aversive medical experience. Paucity of high-quality materials available for heart-related procedures
Peer counseling	Uses direct interaction with peers (either in person or online) who have successfully	High acceptance by adolescents (congruent with peer focus and	Issues of appropriateness/ privacy when direct interpersonal

Intervention	Description	Benefits	Limitations
	managed similar stressful circumstances and thus can serve as a positive role model	developing independence from families)	interaction involved

*Studies done on a variety of populations. Generalizability to children with coronary heart disease (CHD) undergoing invasive procedure unclear.

Table 2: Age-Appropriate Interventions Before Cardiac Catheterization or Surgery

Cognitive Developmental Stage (Piaget)	Approximate Age Ranges	Age-Appropriate Interventions	Timing of Intervention
Sensorimotor period • Learns via sensory input • Separation/stranger anxiety • Minimal conceptual abilities	Birth to 2 years	• Maximize parental involvement in child´s care • Avoid separation from parents whenever possible • Use of transitional objects • Adequate sedation/pain medication	During procedure
Preoperational period • Egocentric, concrete thinking • Illness caused by external events • Learning via hands-on experience • Rudimentary	2 to 7 years	• Books about going to the hospital • Preoperative classes • Medical play • Refocusing during stress	• 15-minute session day before procedure • 6- to 7-year-olds may benefit from earlier intervention

Cognitive Developmental Stage (Piaget)	Approximate Age Ranges	Age-Appropriate Interventions	Timing of Intervention
concept of time/past/future		points • Proximity to caring personnel, favorite toy	(1 week before) • Child questions useful indicator of learning readiness and content
Concrete operational period Logical thinking (cause/effect) emerges • Concept of past and future • Awareness of internal body parts and function • Fear of loss of body parts, disability, loss of control	7 to 11 years	• Information-giving: brief verbal description using age-appropriate terminology • Books about going to the hospital • Medical play: include anticipated sensory experiences • Peer modeling tapes • Coping-skills training • Biofeedback	• Information-giving: initiate 1 week before procedure • For highly anxious and/or experienced children, coping-skills training or biofeedback initiated 6 weeks before procedure
Formal operational period • Abstract thinking available • Independence from parents • Peer focused	12 to 15 years	• Information-giving: include anticipated sensory experiences • Peer counseling • Peer modeling tapes • Coping-skills	• Information-giving: begin at time decision is made • Peer counseling at any point in time • Coping-skills training/biofeedback: 6

Cognitive Developmental Stage (Piaget)	Approximate Age Ranges	Age-Appropriate Interventions	Timing of Intervention
		training • Biofeedback	weeks before procedure

Preparation for Cardiac Procedures

Preprocedure preparation depends, in part, on whether cardiac catheterization or cardiac surgery is planned. Although it has proved efficacious in both situations and there are similarities in the stressors encountered, there are also significant differences. Both types of procedures are viewed as serious events and cause considerable stress for parents and children. In both cases, given limitations in the type of medications that can be used and the potential for side effects with larger dosages, nonpharmacological management of pain and anxiety is important. Many similar stress points are also encountered, including separation from parents, venipuncture, and dealing with strangers in the absence of a trusted adult. Finally, there are overlapping educational issues, including the diagnosis, treatment options, and prognosis.

There are also differences between the 2 experiences that affect preprocedure preparation. Heart catheterizations are often performed under conscious sedation, whereas surgery necessitates anesthesia induction. Furthermore, whereas heart catheterizations can usually be done on an outpatient basis, heart surgery usually requires an extended hospital stay. Pain management, anesthesia induction, scars/incisions, and intensive care unit (ICU) preparation are key areas of concern for the child scheduled for heart surgery. The following paragraphs examine preprocedure preparation specific to cardiac catheterization and cardiac surgery.

Cardiac Catheterization

Cardiac catheterization is a stressful experience that is associated with a high incidence of child behavioral changes, including aggression, separation issues, regression, and anxiety, with more severe effects observed in younger children. Challenges facing health care professionals caring for these patients include increased numbers of children who are undergoing interventional cardiac procedures such as transcatheter atrial septal defect closure, coil occlusion of patent ductus arteriosus, balloon valvuloplasty or angioplasty, and radiofrequency ablation for tachyarrhythmias. These procedures can take as long as 3 to 5 hours and are often performed under conscious sedation, because anesthesia may alter the cardiovascular hemodynamics. Pain and anxiety may not only confound clinical data (blood pressure, cardiac rhythm) but also manifest as distress or lack of cooperation by the child, impeding the success and timely completion of the catheterization procedure. Goals of pre-medication and sedation (or anesthesia) are to decrease anxiety, ensure patient comfort during the procedure, promote amnesia, and facilitate the performance of the procedure so that it may be undertaken as safely as possible.

The child´s response to the stress of cardiac catheterization will be influenced by the child´s age or developmental stage, the child´s perceptions and appraisal or fears, the child´s coping skills, and the parents´ anxiety. Preschool children may fear mutilation and abandonment or separation from parents, whereas older children fear loss of control, invasion of privacy, and bodily harm and/or death. The child´s perceptions may be based on his or her own previous experience with invasive procedures, but even the inexperienced child may have misperceptions based on adult reports of their cardiac catheterization experience and, more frequently, on the child´s television experiences. The cardiac catheterization laboratory resembles an operating room (masked physicians, monitors, and emergency equipment), a sight familiar to many children via television viewing. Stressors and fears need to be explored so that misconceptions or distorted fantasies can be corrected. Assessment of the child´s past coping behaviors may also help tailor the intervention strategy to the child´s preferred coping style or suggest other more effective techniques.

Information Giving/Sensory Experiences

Information about the procedure and validation of the child´s understanding is needed, because many children demonstrate lack of understanding and/or misperceptions about cardiac catheterization. In addition to an age-appropriate explanation of the procedure, anticipatory guidance about sensory experiences including the appearance of equipment in the cardiac catheterization room, personnel wearing masks, use of cardiac electrodes, restraints on the child´s arms, sterile sheets and towels covering the child, and the sounds of monitors beeping and other equipment noises should be provided. Children can be counseled that during the procedure they will generally feel sleepy but may feel the catheter insertion site being cleaned with a cold liquid (Betadine), the pinching or discomfort of the lidocaine injections, and a warm feeling after contrast injection. If general anesthesia is used, sensory information about anesthesia induction may be beneficial. After the procedure, the children need to know that they are usually required to lie flat for 4 to 6 hours. Older school-age children need assurance regarding respect for their modesty and privacy issues.

The method of presentation of medical content is an important consideration. In one of the earliest studies, information delivered to children via a puppet show produced a positive effect on children´s behavioral stress. Other methods of information giving include booklets, videotapes, structured medical play, and/or tours of the catheterization laboratory as well as verbal communication with health professionals.

Cognitive Behavioral Interventions Before Cardiac Catheterization

Refocusing techniques have proved effective for children at various developmental stages, irrespective of whether they have previous experience with heart catheterization. School-age children undergoing cardiac catheterization are generally eager to listen to audio tapes and are highly distractible. Older adolescents also report that using refocusing techniques, such as listening to music, can be helpful. Children and adolescents may perceive increased control over their environment by being given a choice of their favorite music tapes or compact disks and available relaxation tapes.

Comprehensive coping-skills training has been shown to be effective in children undergoing cardiac catheterization. One study describes a comprehensive stress management program including counseling and coping-skills training (controlled breathing, progressive muscle relaxation, biofeedback, guided imagery, and cognitive reframing), which was associated with a positive effect on children´s stress-related behaviors both during and after hospitalization. Parental satisfaction with care and parents´ ratings of children´s behavior after discharge were also more favorable in the experimental group. A similar program targeting mothers of preschool children undergoing heart catheterization was effective in decreasing maternal anxiety and child stress-related behaviors. Guided imagery, when used in isolation, has not proved effective for this younger population, perhaps because it is difficult to sustain for long periods of time. Other studies have also found that distress-reduction effects did not persist when the therapist (coach) was not present, making this strategy less feasible if adequate personnel are not available.

Parent Involvement

Assessment of parental anxiety and stress levels is important, because both contribute to child stress. Information given to parents, as with children, should be individualized on the basis of their cultural and intellectual background, their previous hospital experience and knowledge, and their emotional needs. It is important to provide accurate information and to correct misconceptions that are often related to the experiences of adult family members and friends who have undergone heart catheterization. Parents need information about what to expect during the child´s hospital stay, their own roles, and how to support their child.

Cardiac Surgery

Although there have been dramatic improvements in morbidity and mortality, heart surgery is a major surgical procedure that imposes multiple stressors on children, adolescents, and their parents. Children and families must cope with anesthesia induction, monitoring in an ICU, multiple medical procedures, and a period of recovery in a hospital ward with continued monitoring and increasing activity. Most patients will experience venipuncture, intravenous lines, chest x-rays, taking of vital signs, cardiac monitoring, incisions/scars, bandages/dressings, chest tube removal, and taking of medications.

In addition to the physiological sequelae of surgery and recovery, there are emotional stressors including a surgical procedure 2 to 5 hours long or more, separation from parents, bodily pain and harm, loss of control, and fear of the unknown. Because the heart is a vital organ, fear of a life-threatening event is often present. Overall, the literature suggests that younger children express concern about pain, needles, and strangers and are less likely to identify fear of dying or general anesthesia, whereas adolescents and parents have more concerns about these latter issues.

Most of the research on the stress of surgery and hospitalization has been done in children having minor surgical procedures, with relatively few studies of children undergoing major surgery, such as cardiac surgery. It seems likely that cardiac surgery, with the need for intensive care, several days or more in the hospital, and multiple medical procedures, would cause more anxiety and have a greater

potential for negative behavioral responses than minor surgical procedures and warrant an even greater need for preprocedure preparation.

Information Giving/Sensory Experiences

Many members of the health care team have roles in preparing children and their parents for heart surgery. Initial discussions usually begin with the cardiologist at the time surgery is recommended. Printed materials (booklets, letters, brochures) with information about heart surgery, the hospital and the ICU, and resources for families are often sent from the surgeon´s office when a surgical date is set. The surgeon meets with the parents to review the risks and benefits of surgery so that informed consent can be obtained. Parents should be counseled that unexpected complications can occur requiring medical management that was not discussed before surgery. Older school-age children and adolescents may benefit from participation in selected aspects of these discussions on the basis of their maturity and interest.

Parents often need guidance about what to tell the child before coming to the hospital. For preschool children, a brief explanation given the day before the procedure is appropriate (e.g., "We will be going to the hospital and staying a few days. The doctor will do an operation to help your heart work better."). Most older children will already have some awareness that they have a heart problem, thus providing the basis for a conversation about the need for an invasive procedure. Preprocedure preparation is usually most effective for this age group if initiated at least 1 week before hospitalization. The child life specialist can provide further individualized medical play to facilitate the child´s understanding and sense of self-mastery.

Many topics need to be reviewed before cardiac surgery. Parents, in particular, need information regarding preoperative testing and routines, anesthesia, and the operation itself. Information should be specific to the planned surgical repair, because many aspects of postoperative care will vary among patients, such as length of intubation, use of monitoring equipment, surgical incision, and expected stay in the ICU. A tour of the hospital, including a hospital room, the playrooms, and other common areas, is often helpful for parents.

In the literature, there are discussions of the content to include in ICU preparation, but there are no research data on either child responses to ICU preparation, appropriate level of detail to communicate to the child, or the efficacy of various preparation strategies. It is important to note that preprocedure information and exposure to the ICU environment may actually increase anxiety in some children, particularly younger children, those with previous hospital experiences, and those who are highly anxious. Topics relevant to preparation for the ICU include the environment, equipment, and the personnel the child will encounter. Many patients are sedated and receive intravenous pain medication in the first 12 to 24 hours after surgery and will experience minimal recall regarding equipment or events during this time. Early extubation (in the operating room or within several hours after surgery) is common in many institutions, so children may have minimal recall of being intubated. The child´s sensory experience of being in the ICU environment may include sights (monitors, bright lights, many people, equipment), sounds (beeping machines, voices), and sensations (feeling sore, lines and dressings, feeling thirsty).

Important recovery-related topics include the benefits of early ambulation (sitting up, walking in the hall, going to the playroom even when you´re sore because it helps the body heal), coughing and deep breathing (with practice using a spirometer), and when usual activities such as school, gym class, and sports may be resumed.

Cognitive Behavioral Interventions Before Cardiac Surgery

Information giving in conjunction with coping-skills training has proved effective in children undergoing cardiac surgery. Campbell et al compared 2 methods of preparing children (ages 4 to 12 years) for heart surgery and found better in-hospital and post-discharge adjustment in children who received coping-skills training than in children who received information only as routinely provided. Children who had received coping-skills training showed less behavioral distress during hospitalization and, after discharge, better school performance and earlier improvement in functional health status. Parents also expressed greater confidence in the care-giving role both during hospitalization and after discharge. The experimental group (both children and parents) received both problem-focused and emotion-focused coping-skills training, including conscious breathing, progressive muscle relaxation, and guided imagery.

Because children will be exposed to many aversive procedures during their hospital stay, learning simple coping strategies such as refocusing via counting, singing, or blowing during stressful events is helpful. Favorite stories or a video after a stressful event may help a child relax. Bringing a favorite toy or other transitional object can be very reassuring to the child.

Parental Involvement

Parents must cope with their own fears and anxieties while maintaining their parenting role in an unfamiliar environment. Cardiac surgery and postoperative recovery in the hospital are stressful for parents, especially mothers, irrespective of the complexity of the surgery needed. Parents may feel guilty about the child´s needing surgery and feel responsible for putting them through the stress of the procedure. They are often anxious about complications and long-term outcomes.

Although most preparation programs are aimed at children, parents also benefit from the interventions, feeling better able to support their child in the hospital. Parents should have an opportunity to ask sensitive questions without the child present and should be made aware of social work and other available support systems. Reassurance should be given to the parents that they will remain near the child, that they will be encouraged to stay with the child whenever possible (subject to reasonable hospital restrictions), that staff will be supportive of their family´s needs, and that the child´s pain will be well controlled. Anticipatory guidance regarding the child´s appearance after surgery as well as the impact of hospital experiences on children´s behavior (overt resistance, passive or regressive responses), both during and after discharge, is also needed.

Parents have a critical role in providing emotional support to their child and should be prepared and encouraged to participate in normal parenting routines (such as feeding, bathing, playing, reading stories, cuddling) while the child is hospitalized. Rooming-in should be encouraged when possible, especially for younger children,

to reduce the stress of separation. Parents can learn to support their children by coaching them through procedures using refocusing and relaxation techniques.

Definitions:

Levels of Evidence for Efficacy of Interventional Methods

A. Data derived from multiple randomized controlled trials
B. Data derived from single randomized trial or nonrandomized studies
C. Consensus opinion of experts

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

- Multiple randomized controlled trials
- Single randomized trial or nonrandomized studies
- Consensus opinion of experts

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Improved development, implementation, and evaluation of preprocedure programs for children and adolescents who must undergo invasive cardiac procedures

POTENTIAL HARMS

Not stated

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Personnel: Training and Roles/Resources

Invasive cardiac procedures are complex, generally requiring a diverse team of health care providers (with diverse educational backgrounds) including physicians, nurses, and technicians across several patient care units (e.g., clinic, catheterization laboratory, recovery room, and inpatient units). Therefore, ongoing education for all of these providers, aimed at increasing awareness of and sensitivity to the needs of children and families, is recommended. Educational issues to be addressed include child developmental stages, use and importance of child-sensitive language, children´s coping methods, parental coping methods,

and use of appropriate interventions during stress points (e.g., refocusing techniques).

Pediatric Cardiologist and Primary Care Physician

The doctor-family relationship is integral to the preprocedure process and outcomes. Primary care physicians are usually involved in the initial diagnostic and referral process and frequently provide initial information and support to the family. They also have a significant role in the follow-up care of the child and family.

The family´s relationship with their child´s pediatric cardiologist and cardiovascular surgeon is paramount. Communication with these specialists provides the foundation for understanding the diagnosis, prognosis, and treatment options, including the need for invasive procedures. These physicians are also the leaders of the health care team and are thus in a pivotal position to foster a team approach that incorporates and values preprocedure preparation programs.

Advanced Practice Nurses (Clinical Nurse Specialist, Pediatric Nurse Practitioner, Nurse Clinician)

Advanced practice nurses (APNs) who are specialty or unit based can assist in the preparation of children for invasive procedures. These individuals usually hold a master´s degree and are prepared with an educational background in pathophysiology, child and family assessment, child psychology, and child and family adjustments to chronic illness. Interactions with the child and family before the procedure may have facilitated the development of a trusting relationship between the APN and the child and family. APNs are well positioned to provide preprocedure preparation because of their focus on psychosocial adjustment, disease management, and provision of continuity of care. As a result, they can facilitate a detailed understanding of the pathophysiology of the defect, surgical interventions, and anticipated recovery and potential issues (e.g., morbidity, activity restrictions, school restrictions) and offer anticipatory guidance (e.g., nutrition, developmental response to events).

Pediatric Nurses

Historically, pediatric nurses provided preprocedure preparation during hospitalization the night before the procedure, although this role has been curtailed by the transition to same-day procedures. Pediatric nurses continue to be instrumental in providing procedure preparation for hospitalized children and provide these services in outpatient clinics and office settings as well.

Child Life Specialists

Child life specialists are health professionals who focus on enhancing the normal growth and development of children and families dealing with health-related issues. They have a bachelor´s degree with course work in child development, child and family psychology, and early childhood education. Goals of the child life specialist include (1) providing play experiences, (2) providing psychological preparation for children by presenting developmentally appropriate information

about health care–related events and procedures, and (3) establishing therapeutic relationships with children and parents to support family involvement in each child´s care. Play in all its forms is a key modality used, and child life specialists provide needed expertise in medical play for children undergoing invasive medical procedures. They can assist in desensitization procedures for young children and medical play and recommend referral to a psychologist or other team member if indicated. In addition, they can provide a sense of normalcy through provision of routine, structure, and developmentally appropriate activities during hospitalization.

Social Workers

Social workers are integral to most pediatric cardiology programs, offering much-needed expertise regarding the impact of chronic illness on children and families. The role of the medical social worker is diverse and includes comprehensive child and family assessment, psychosocial support, counseling, stress management, crisis intervention, education, advocacy, and helping families meet tangible needs. They facilitate ongoing support and intervention via identification of available community resources with referral as needed. Most social workers in a medical setting are prepared at the master´s level (MSW).

Child and Adolescent Psychiatrist, Pediatric Psychologist, Behavioral Pediatrician

Unfortunately, most pediatric cardiology centers have limited access to these highly trained specialists, but they may be able to use their services on a referral or consultation basis. Indications for referral include child or parental depression, incapacitating anxiety or fear, end-of-life decisions, persistent behavioral adjustment problems, prolonged hospitalization, and/or ineffective coping mechanisms. Consultation with these specialists in the development and/or review of new educational materials and the content of the overall procedure-preparation program is highly desirable.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Getting Better
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

LeRoy S, Elixson EM, O'Brien P, Tong E, Turpin S, Uzark K. Recommendations for preparing children and adolescents for invasive cardiac procedures: a statement from the American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in collaboration with the Council [trunc]. Circulation 2003 Nov 18;108(20):2550-64. [100 references] PubMed

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2003 Nov 18

GUIDELINE DEVELOPER(S)

American Heart Association - Professional Association
American Stroke Association - Disease Specific Society

SOURCE(S) OF FUNDING

American Heart Association

GUIDELINE COMMITTEE

American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in Collaboration With the Council on Cardiovascular Diseases of the Young

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Writing Committee Members: Sarah LeRoy, RN, MSN, Chair; E. Marsha Elixson, RNc, MS, Cochair; Patricia O´Brien, RN, MSN; Elizabeth Tong, RN, MS, FAAN; Susan Turpin, RN, MS; Karen Uzark, RN, PhD, FAAN

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a Disclosure Questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available from the American Heart Association Web site:

- HTML Format
- Portable Document Format (PDF)

Print copies: Available from the American Heart Association, Public Information, 7272 Greenville Ave, Dallas, TX 75231-4596; Phone: 800-242-8721

AVAILABILITY OF COMPANION DOCUMENTS

None available

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI on September 13, 2004. The information was verified by the guideline developer on October 13, 2004.

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Date Modified: 1/10/2005